



Quarterly Issue

Winter Edition 2003

From the Director

Michael J. Ward, Ph.D.

### **Preserving the Safety Net of Services for Individuals with Disabilities and their Families**

As the 2003 Legislature begins, the State of Arizona is facing the worst budget crisis in recent history. State funding for the Division of Developmental Disabilities (DDD) has been reduced by over \$7 million in the past two years. The Division has absorbed these reductions by eliminating a number of administrative positions, reducing consultant services (such as those that provide behavioral management programs for clients) and freezing services to those who are not Medicaid-eligible (State-only). For all populations (children, Title XIX eligible, State only), the Division has drastically reduced or eliminated all services considered "non-essential."

**The Division of Developmental  
Disabilities is not alone in facing cuts.**

The Rehabilitation Services Administration (RSA) has already eliminated 27 full time employees from a cut of \$200,000 in state monies and the loss of the associated \$738,900 in federal match monies.

Similarly, the Arizona Health Care Cost Containment System (AHCCCS) has also reduced administrative staff. Although, these reductions have been reported to be minor. Despite the fact that reductions to both RSA and AHCCCS have been limited to administration, programs and client services will inevitably be affected.

The 2003 Legislature will be seeking to trim an additional \$280 million from the current State Fiscal Year (SFY) 2002-2003 budget and have to address an additional \$1 billion anticipated shortfall for SFY 2003-2004. All agencies and programs will be asked once again to scrutinize their budgets and propose reductions. Again, vulnerable developmental disability populations will include those who receive children's services and also those not eligible under Title XIX, Medicaid (State-only). Depending on the extent of the mandated reductions, the Division of Developmental Disabilities can attempt to reduce the number of its administrative positions - severely affecting the Division's basic operations including: program eligibility and evaluation, support coordination, contract procurement, reimbursement and monitoring of necessary

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services for persons with developmental disabilities. However, if mandated reductions are more extensive, reductions in essential services will need to be made.

The following is just one example of how trying to save money by the Division of Developmental Disabilities could cost the State more money in the future by having to provide extensive and expensive services. Prior to recent budget cuts, families with children with developmental disabilities received funds for a certain number of hours of respite care each year so that families could hire someone to take care of their children's specialized needs. This much-needed break rejuvenated many families so they could continue providing extensive care for their children and prevented families from having to place their children in a more restrictive, less desirable, institutional setting. Therefore, if respite services are cut, then more children are at risk for placement in institutional settings and an increased need for out-of-home services at a higher cost to the State. Families are at risk for more stress related illness and behavior.

This issue of Benchmarks has been devoted to stories of five families with children and young adults with developmental disabilities. Yes, these stories may tug at your heart and bring tears in your eyes. These stories may bring to mind sympathy and concern as to how these parents hold it together and provide the special care their children need on a daily basis.

When we requested these stories, we received many more than we could include in our newsletter.

**Many families are hurting.**

Our purpose is not to evoke sympathy, but to inform our legislators, our new Governor, and anyone in a position to affect the budget process that Arizonans with developmental disabilities and their families have already sustained the maximum reduction in essential services. There are families who are not eligible for Medicaid and previously relied on respite care falling through the Safety Net. Further reductions will only increase the number of families who fall and become a greater burden on State dollars.

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By Stacy Fairfield, Parent of Amanda

Four years ago, DDD (Division of Developmental Disabilities) authorized habilitation for my daughter Amanda and a habilitation provider was found who would work with her. Amanda had been improperly diagnosed as retarded, rather than autistic, and was receiving the wrong medications. She was both verbally and physically aggressive. The school she attended had recommended home schooling and had repeatedly told Amanda that if she didn't behave she would go to jail. The school had advised Amanda's mother that institutionalization was the only option open to her.

Within a month of receiving habilitation, from DDD I was encouraged enough by the results that I sought a new evaluation which indicated autism and Amanda was placed on the correct medications. She also began receiving constant behavioral therapy at that point.

This past summer, Amanda was able to go on a two week vacation without a service provider. Amanda's school days are positive experiences. She makes choices and states her needs without a trace of anger or aggression. Amanda works hard to be part of her community and is looking forward to working with animals when she is older.

## INFORMATIONAL NEWS!



The Forty-sixth Legislature First Regular Session for 2003 begins Monday, January 13th with Governor Napolitano's State of the State address. Governor Napolitano will roll out her expectations and emphasis for the upcoming year.

In lieu of the Spring Edition of the BENCHMARKS Newsletter, the Governor's Council on Developmental Disabilities will be sending out our Annual Report for 2002. If you would like to receive a copy of the Annual Report and are not sure that your name is on the mailing list or if your information has changed, please notify our office at: 602.542.4049.

There is currently Council Membership openings for the Governor's Council on Developmental Disabilities. We are especially looking for people with developmental disabilities and family members from unserved/underserved communities.

Inserted in this issue of the BENCHMARKS is the **Community Input/Suggestions Form**. We encourage you to complete the form and mail or fax it to the Governor's Council on Developmental Disabilities. Your input is vital to helping the Governor's Council address the issues and concerns of family members and consumers.

**By Cheryl Storm, Parent of Taylor**



I am a single mother of my very special daughter Taylor. She is four years old and was born three months early. Taylor was declared disabled at birth and receives SSI Title 19 benefits. I have not worked since her birth due to all her medical needs, as well as her developmental delays in all areas. I do not know when I will be able secure any independent income without jeopardizing Taylor's services or care.

Taylor has ten physicians. She has four therapists that come to our home to work with her one-on-one and they show me how to work with her special needs. A counselor comes to our home to help with Taylor's sleep disorders due to medical trauma. I rarely get much sleep because I am her sole caregiver.

The first two years with Taylor I had no help at all. Through DDD (Division of Developmental Disabilities) I receive respite care and Taylor now receives habilitation. These services help tremendously, giving me a chance to breath some.

Without Taylor's speech therapist; I still would not know why my daughter couldn't and still can't talk! I would still be visiting many physician's offices pleading for answers. The therapists work with Taylor's oral sensory issues and her music therapist helped her to speak her first words. The physical therapist keeps me abreast of the areas that I need to help Taylor work on physically to build up her muscles. Her occupational therapist works on attention span, focus, and coordination. If these budget cuts happen as addressed, my daughter and many other children may not be able to function to the best of their potential.

I have struggled financially for four years to pay our monthly bills. I rely on cash assistance at \$204.00 monthly, food stamps (approx. \$179.00) monthly, Taylor's SSI benefit's \$300.00 monthly (this varies based on the dates I receive child support checks), child support check \$393.00 monthly. My income is never stable, I continually have to beg for assistance from charitable organizations. There is never enough funds to pay the bills, buy diapers, pay for auto insurance or auto repairs.

Taylor needs to continue receiving one-on-one intervention to help her be a productive adult in the community. This is her best chance and that is what any parent would want for their child.

Please don't take any of these services from her or any other child with special needs. I ask you to please consider the children's best interest when making your decisions regarding the state budget.



By Sylvia Sloan, Parent of Daniel



I wanted to write this letter to you, in the hope that it will help you understand what a parent of a special needs child and the child goes through. I would like you to understand the decisions that you make today will effect the lives of many children including my son. I am especially concerned about the budget cuts.

Daniel is eleven, after a four month fight with doctors to find out what was wrong with my child; he was diagnosed with Cystic Fibrous and reflux. Two years later Daniel was approved for SSI Title 19 benefits. I am a single parent and I receive \$545.00 from SSI, \$204.00 from cash assistance and \$170.00 from food stamps. For the second time in my life I had to get help to pay my electric bill. I am not proud of having to get help. This way of life is not what I choose to teach my son. I want him to have hope for his future. Daniel was born a month early, the reflux caused him tactile problems. He received speech therapy (provided by the state) at a very early age. The speech therapy did help him to start eating better. However, he is still on a feeding pump and the state provides for special formula and pedalite. When Daniel is sick he has to have a machine called a SVN that administers medication while at the same time he gets CPT treatment (this is where you pound your child to loosen mucus so that it can be coughed out). I administer the treatments every two hours around the clock when he is sick. As a single parent and working, I may get two hours

sleep. The respite that the state provides for me is vital not only for my son's survival but also mine.

Daniel has more doctors than I can count, primary care doctor, pulmonary specialist, gastrologist, nutritionist, sinus surgeon, just to name a few. Each doctor comes with their own set of mazes to get through, to get appointments, approval, and help.

Keeping a job has been a nightmare. I have worked for two major companies in the last twelve years. I have received many awards for both jobs but that does not make a difference if you can't make it into work. I have had to get doctors notes to take off from work an hour early each week because Daniel had five pharmacies that I had to get his medications from. I was laid off from my first job and the last job I had with Federal Express I lost because Daniel was in the hospital so much. When you have a sick child every employer wants to know if it will affect your job performance and for how long.

The DES work program helped me get into real estate school. I still have hope that I will be able to complete school and get some kind of a life back. I have not completed my schooling yet because Daniel has been very ill again. Somehow we need to find jobs for people that have special needs children.

Daniel only attended one week of school this past year. He did have some home schooling when he was well enough.

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The kind of medical problems Daniel has left him fighting for his life. Last year alone he had pneumonia several times, complete kidney failure from the antibiotic he had to take for the pneumonia causing him to go on dialysis, sinus surgery, and other complications. These medical problems have led to mental problems. As his mother, I continue go through all the red tape to get him what he needs. I understand that you need policies, paperwork and appointments. But do you understand how hard it is to keep up with everything physically, mentally and financially? I do not want to be on the system, but can you tell me any other way that I can do it? Please consider your choices. Please find some way to help us and some way to show us how we can help ourselves.

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**By Marlene DeForrest, Parent of Hannah**

Screaming, crying, hitting her head and face, pulling out her hair, writhing on the floor: this is how my daughter, Hannah, spent most of her days when she was 20-24

months old. Prior to that time, she was a happy toddler that everyone enjoyed. She had normal development which included several one to three word phrases. But at 20 months old, she was losing her language skills and eventually couldn't talk at all. Hannah was finally diagnosed with autism and a seizure disorder. Through the help of a

program called Applied Behavioral Analysis (ABA), we began to get her behavior under control and she started to regain her language.

Hannah began special education at Saguaro Ranch Elementary School at the age of three. After moving into the Washington School District, she was transferred to Manzanita Elementary School. Her teachers and therapists were very willing to hear about her ABA program at home and applied the same principles at school. They stayed in close contact with me which I consider to be a key in Hannah's success. She spent two years in special education preschool and was so successful that she was able to be enrolled in a typical kindergarten classroom with the support of an aide. The school allowed me to be on the team that interviewed prospective aides for Hannah. This a great example of the value they place on a mom's insight to her child.

Manzanita school has been very supportive by providing training in behavior modification for Hannah's aide, consulting with Hannah's ABA consultant, and using a team approach to setting up her behavior program at school. This approach allows for consistency between school and home. Once again, this a big key to her success.

Hannah is a happy child again and she loves school. In fact, she is doing so well that it is anticipated that she will be able to attend typical classrooms without support within the next year or two. Clearly, this could not have been possible without the openness, support, and consistency that have been part of her special education.

By Nancy Herold, Concerned Parent

**Cuts, cuts, cuts**, that's all I've been hearing. Each time I talk to someone in DDD (Division of Developmental Disabilities) all I hear is that a program or service has been cut and will no longer be available.

It is rumored that the case managers will forfeit four days of pay this year. Children that are state eligible only will no longer receive services. What has happened within our state that has brought us to this?

As a parent of a special needs child, I appreciate the services my child receives. We receive respite and habilitation services through DDD. Most of the equipment she uses on a daily basis comes from DDD. She has weekly physical, occupational and speech therapies. We were without a physical therapist for three months and by the time a new physical therapist came on board, my daughter's condition had worsened. Her need for weekly therapy along with a continuation of exercises at home has kept her body and mind alert and responsive. Without their help she would not be doing as well or developing skills to ensure whatever independence she can. My child's needs are long term and our insurance will not cover the length of care she needs, nor do they consider her dignity or quality of life.

On behalf of my daughter and parents who have children with disabilities, whose quality of life depends on the services they receive, please stop the cuts and consider that each dollar amount affects a precious child with special needs.

## HEAVEN'S VERY SPECIAL CHILD



A meeting was held quite far from earth,  
"It's time again for another birth."  
Said the Angel to the Lord above.  
This special child will need much love.

His progress may be very slow.  
Accomplishments he may not show,  
And he'll require extra care, from the  
Folks he'll meet down there.

He may not run, laugh or play.  
His thoughts may seem quite far away.  
In many ways he won't adapt,  
And he'll be known as handicapped.

So let's be careful where he's sent  
we want his life to be content.  
Please Lord, find the parents who  
Will do a special job for you.

They'll not realize right away  
The leading role they're asked to play.  
But with this child sent from above,  
Comes the stronger faith, and richer love.

And soon they'll know the privilege given,  
In caring for their gift from Heaven;  
Their precious charge, so meek and mild,  
Is **"HEAVEN'S VERY SPECIAL CHILD."**

~Author Unknown~

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## **BENCH MARKS**

### **GETTING THE JOB DONE**

#### **Arizona Governor's Council on Developmental Disabilities**

**For more information call:**

**602.542.4049**

**Toll Free 1.800.889.5893**

**TTY 602.542.8920**

**Visit or web page**

**[www.de.state.az.us/gcdd](http://www.de.state.az.us/gcdd)**

Fax or e-mail comments and story ideas to:

**[Cynthia Gafford, Editor](#)**

**602.542.5320 fax**

**e-mail [cgafford@mail.de.state.az.us](mailto:cgafford@mail.de.state.az.us)**

#### **Americans with Disabilities Act (ADA) Statement**

Under the Americans with Disabilities Act (ADA), the Governor's Council on Developmental Disabilities (GCDD) must make a reasonable accommodation to allow a person with a disability to take part in a program, service, or activity. For example, this means that if necessary, GCDD must provide sign language interpreters for people who are deaf, a wheelchair accessible location, or enlarged print materials. It also means that the GCDD will take any other reasonable action that allows you to take part in and understand a program or activity, including making reasonable changes to an activity. If you believe that you will not be able to understand or take part in a program or activity because of your disability, please let us know of your disability needs in advance if at all possible. This document is available in alternative formats by contacting:

**[Governor's Council on Developmental Disabilities](#)**

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**Arizona Governor's Council on  
Developmental Disabilities  
1717 West Jefferson (SC074Z)  
Phoenix, Arizona 85007**